

Thinking
About
An Orientation Guide
Outcomes

Thinking About *An Orientation Guide* Outcomes

This is one of a series of guides that provide an introduction and orientation to using a personal outcome approach to measure quality in services and supports for people with disabilities. Titles in the series include:

Designing Quality: Responsiveness to the Individual

Thinking About Outcomes: An Orientation Guide

Making Choices: Supporting People in Decision Making

Enhancing Rights: A Proactive Approach

The Council on Quality and Leadership is dedicated to ensuring that people with disabilities have full and abundant lives. The Council works with service and support providers to enhance and support their efforts towards quality improvement.

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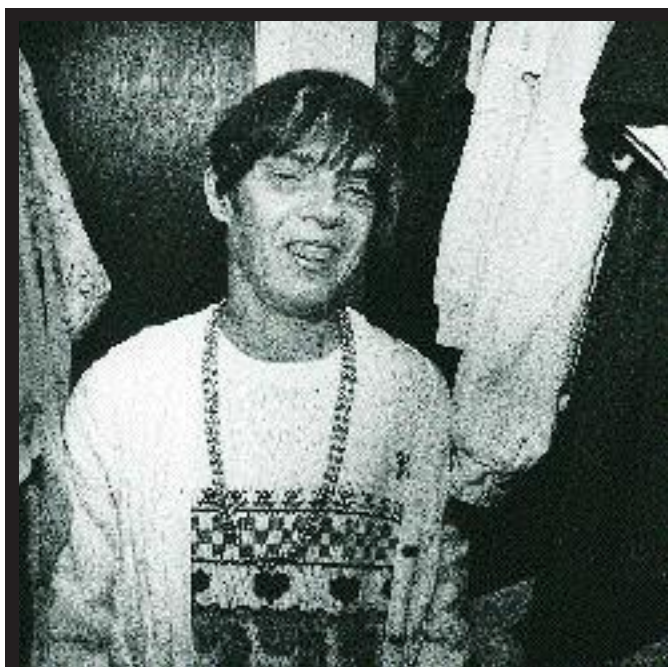
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With the publication of the *Outcome Based Performance Measures* in 1993 and the *Personal Outcome Measures* in 1997, The Council on Quality and Leadership in Supports for People with Disabilities (The Council) signaled a new focus and offered a new challenge to the traditional approach to quality assurance. The Personal Outcome orientation reflects a dramatic shift in how quality is defined and approached in services and supports for people with disabilities. The outcomes consist of specific items such as individual choice, dignity, respect, social inclusion, security, personal relationships, and rights that people with disabilities indicate is most important to them.

The outcomes people choose represent their major life goals and fundamental values. Thinking about outcomes for people causes us to focus on what is most important to them. There is a vast difference between the outcomes we want in our lives and the means by which we achieve our outcomes. Implementing high-priority outcomes is often more confusing than initiating and doing short-term activities. This is why most people tend to focus on daily routine rather than long-term goals. Professionals in disability and other human service fields are no exception — they tend to become preoccupied with next week's objectives rather than address strategic outcomes.

The vocabulary and literature of disability and human service professionals emphasize new programs and methods. Sometimes, we pay more attention to new techniques and technology than to people's definition of their valued outcomes. The means to the end become confused with the outcomes people want



The Council's personal outcome orientation

*refocuses attention on the outcomes **that people can expect** from the services and supports they receive.*

for themselves. For example, we become preoccupied with the specifics of supported living or attendant care and forget what personal outcome will be enhanced by providing supported living or attendant care.

The Council's personal outcome orientation refocuses attention on the outcomes that people can expect from the services and supports they receive.

A focus on personal outcomes redirects attention to the following questions:

- ▶ **Why do we provide the service or support?**
- ▶ **What personal outcomes do we expect from the support or service?**
- ▶ **What outcome will this new technique or technology enhance?**

As a result, outcomes become more important than organizational process. Quality is best measured by our responsiveness to people rather than compliance with process requirements. Linking quality to peoples' preferred outcomes transfers power from the professional and the bureaucracy to the people they serve.

The ultimate worth of a support or service is in its contribution to an outcome for a person. Compliance with organizational process in the absence of outcomes for people does not further quality in services and supports.

Your Personal Life Priorities

Reflect upon the priorities in your own life. Where are your priorities? What do you value the most? What values or priorities are most important to you?

Take a few minutes and list the ten most important priorities in your life. (Just write them as they come to you. They do not need to be ranked in order of importance.)

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

The Life Priorities of Other People

The priorities you just listed are probably similar to those of people who have participated in The Council's seminars and workshops. When we ask participants to identify their values and priorities, they generally respond with the following items:

- ▶ **health**
- ▶ **family**
- ▶ **work**
- ▶ **freedom**
- ▶ **God/faith/religion**
- ▶ **money**
- ▶ **sex/love/relationship**
- ▶ **accomplishment/contribution**
- ▶ **friends**
- ▶ **privacy**
- ▶ **security**
- ▶ **home**
- ▶ **autonomy**

Priorities of People With Disabilities

Now that you have identified your priorities and have read the priorities that people report in The Council's seminars, consider the following questions:

Do people with disabilities share our general list of priorities and life values?

or

Do people with disabilities have their own list of priorities and life values?

Not surprisingly, people with disabilities have the same priorities and want the same outcomes in their lives as other people.

Personal Outcome Measures

Based on individual and focus group meetings with people with disabilities, The Council currently features twenty-five (25) personal outcomes.

IDENTITY

- People choose personal goals.
- People choose where and with whom they live.
- People choose where they work.
- People have intimate relationships.
- People are satisfied with services.
- People are satisfied with their personal life situations.

AUTONOMY

- People choose their daily routine.
- People have time, space and opportunity for privacy.
- People decide when to share personal information.
- People use their environments.

AFFILIATION

- People live in integrated environments.
- People participate in the life of the community.
- People interact with other members of the community.
- People perform different social roles.
- People have friends.
- People are respected.

ATTAINMENT

- People choose services.
- People realize personal goals.

SAFEGUARDS

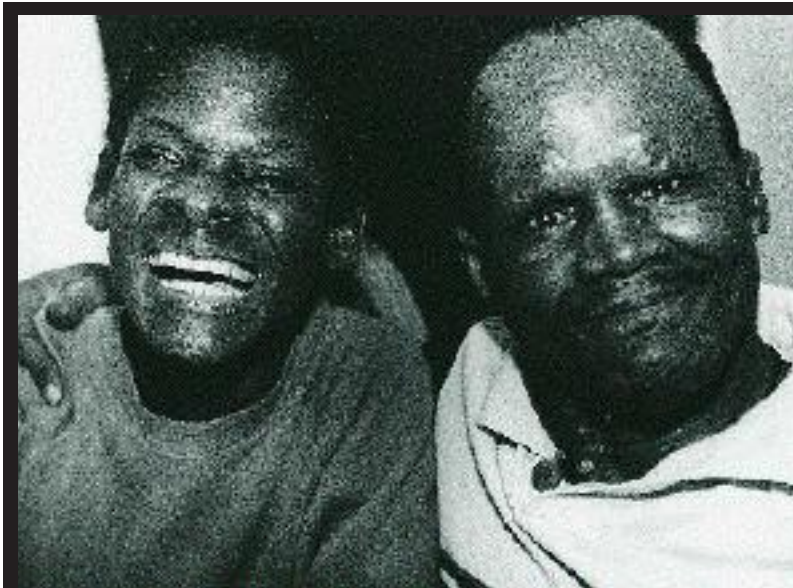
- People are connected to natural support networks.
- People are safe.

RIGHTS

- People exercise rights.
- People are treated fairly.

HEALTH AND WELLNESS

- People have the best possible health.
- People are free from abuse and neglect.
- People experience continuity and security.



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and want the same outcomes in their lives as other people.*

Supports and Services

Supports and services are different from outcomes. Supports and services are individual and organizational activities that enable and assist people to achieve outcomes. Consider the range of supports and services provided by you or your organization to people with disabilities. Some typical service categories are listed below. Within each category, list services that you or your organization provide(s).

LIVING

EMPLOYMENT

EDUCATION

INDIVIDUAL SUPPORTS

LEISURE

ORGANIZATIONAL SUPPORTS

Why Do You Provide the Supports and Services?

You provide supports and services to people with disabilities to assist and enable them to achieve outcomes. More specifically the answer to the question, Why do you provide supports and services?, has two components:

1. Services and supports relate directly to an outcome: When services and supports do not produce outcomes, they become ends in themselves. The means to an outcome become confused with the outcome itself. For example, record-keeping and habilitation meetings occur, but they are important only if they contribute to outcomes.

2. Services and supports relate to outcomes identified by the person: We are concerned about personal, not organizational outcomes. Supports and services are means to outcomes. As such, the most important supports and services are those connected to the priority outcomes in peoples' lives. Different people will have different priority outcomes. One person may want many friends and constant social engagement, while another may value privacy and reflection.

The challenge for individuals and organizations is to provide individualized supports and services that promote and enable people to achieve their designated outcomes.

The outcome of a service or support is not the unit of service or support. Rather, the outcome is the reason that the unit of support is provided. Consider the examples provided in the table below:

This Organizational Support		This Personal Outcome
assistive technology	C o n t r i b u t e s t o	use of environment work productivity
psychiatric rehabilitation		connection to natural support networks
behavioral program		community interaction
attendant care		living in integrated environments
personal-hygiene training program		having friends
job coaching		having economic resources

Asking Why

Sometimes, even when we focus on outcomes rather than organizational process, and even when we concentrate on personal outcomes rather than organizational outcomes, we still miss the meaning of outcomes. We do this when we define outcomes as discrete behaviors. Outcomes are more than behaviors.

The skills and behaviors that people possess provide them with the option to engage in social activity. The social context for behavior gives value, esteem, and meaning. Without a social, cultural, or intellectual context, behavior has no meaning or value.

Beyond individual behaviors, outcomes represent performance capability (capacity). Consider the following examples:

We employ assistive technology to enable people to communicate so that they can interact with other members of the community, or to enable them to indicate that they want to be left alone, or to enable them to find employment.

We design behavior interventions to reduce self-abusive behavior, so that people maintain health and demonstrate socially normative behavior, interact with other members of the community, play different social roles, and decide how to use their free time.

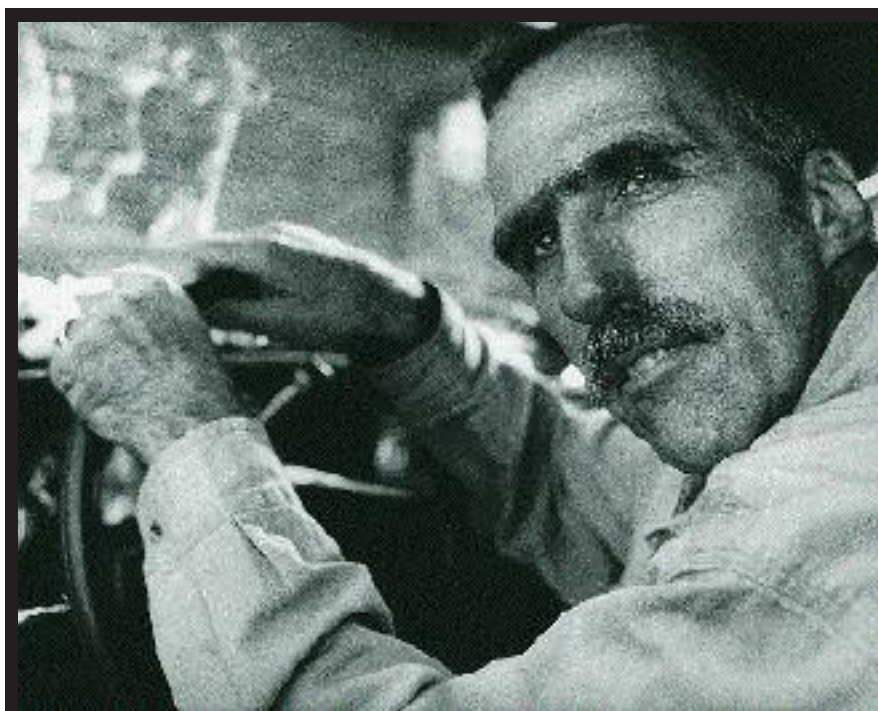
Quality in supports and services is related to the performance that becomes possible because of the organizational process. Providing assistive technology and eliminating self-abusive behavior are not outcomes. These service and support activities make outcomes possible.

You can often resolve the confusion between behaviors and performance by asking the question why. Why does the organization provide assistive technology? Why do we want to eliminate the disruptive behavior? So that people are no longer disruptive? No, we want to eliminate disruptive behavior so that people can behave in a normative manner and thus achieve a range of outcomes.

Remembering the following guidance will help you keep focused on outcomes:

When outcomes seem unclear, keep asking why services and supports are provided, until the response is an outcome.

*Personal Outcome Measures are so powerful
because they focus
on what is most important to people.*



The Power of Personal Outcomes



After looking at the Personal Outcome Measures, many people remark “these are all so simple and basic. This is what we all want in our lives.” The Personal Outcome Measures are so powerful because they focus on what is most important to people. The strength of personal outcomes flows from a focus that is:

Simple. The personal outcomes are short, clear, and written in plain English. They are easy to explain to families, friends, elected officials, and government representatives.

Memorable. As people describe their personal outcomes, their stories remain etched in our memories.

Powerful. The Personal Outcome Measures define for each staff, family member, friend, and volunteer the priority personal outcomes for the person. Personal outcomes magnify the energy of the organization.

Revolutionary. The personal outcome focus empowers the person receiving services and supports. His or her own definition of personal outcomes replaces professional and governmental consensus about “what is quality.”

The Future. The programmed approach to services and supports, requiring standardization, and compliance with process is obsolete. Responsive services will promote the finest in diversity and differences.

At the same time, the personal outcome focus is:

Not A Product. The personal outcomes focus is on the individual’s own definition of importance and worth in his or her life. Unlike a product with a stable shelf life, personal outcomes are unpredictable, yet discoverable.

Not Appealing to Everyone. Individuals and organizations that are attracted to professional or governmental control of the definitions and indicators of quality will not be drawn to the personal outcome focus.

Not Instantly Successful. The personal outcome focus may require significant adjustments. Changing organizational systems in response to people is more complex than ensuring compliance with process.

Not Forever. At some point in the future, the revolutionary becomes routine. At that point, the personal outcome focus will be embedded in the values and principles of the culture that continue to sustain progressive organizations — individualization, inclusion, and legal rights.

(A note of recognition to Al Ries (1997) Focus: The Future of Your Company Depends Upon It for the focus analysis framework.)

The Challenges of Personal Outcomes

The personal outcome orientation challenges organizations and professionals to reverse authority and power relationships. Primary challenges include the following:

For Professionals. The development of services and supports around outcomes for people stretches the role of the organization's employees, especially those professionals performing assessments and evaluations. In fact, the purpose of assessment and evaluation changes.

In the past, the development of goals followed the process of professional assessment. The purpose of professional assessment and evaluation was to design a service plan. The use of personal outcomes reverses the relationship between assessment and planning. Personal outcomes require that professionals play two distinct roles — that of *learner* and that of *facilitator*.

The first role is that of learner. Personal outcomes require learning before acting. The professional must first understand the person's prioritized outcomes. This understanding requires that professionals listen, observe, ask, discover, question, and redirect. The professional learns what the person expects from the services and supports rendered. This learning precedes any decisions about what role the professional might play in the provision of supports and services.

The identification of a person's priority outcomes enables the professional to ask the question "what skills, abilities, and knowledge can I use to facilitate this outcome?" Very often, assessment may identify particular methods that the

professional can use in facilitating the outcome. Assessment provides information about processes and methods for accomplishing outcomes. Assessment, by itself, does not identify outcomes. People define their own outcomes; assessment provides information about how the professional may facilitate that outcome for the individual.

This evolving role requires that professionals act as patient listeners, observers and learners before they render services and supports.

For Programs. Programmed services and supports are ill equipped to facilitate personal outcomes. Programs are professional and administrative creations that provide structure and order for the organization. Programs are based on the assumption that similar people desire similar goals, and that a common process can facilitate those outcomes. However, personal outcomes emphasize individuality, uniqueness, and differentness. Not only do different people define outcomes in a very individual manner, but they may also require different organizational services and supports to achieve those outcomes. Over time, the same individual will need different services and supports as his or her circumstances and desired outcomes change.

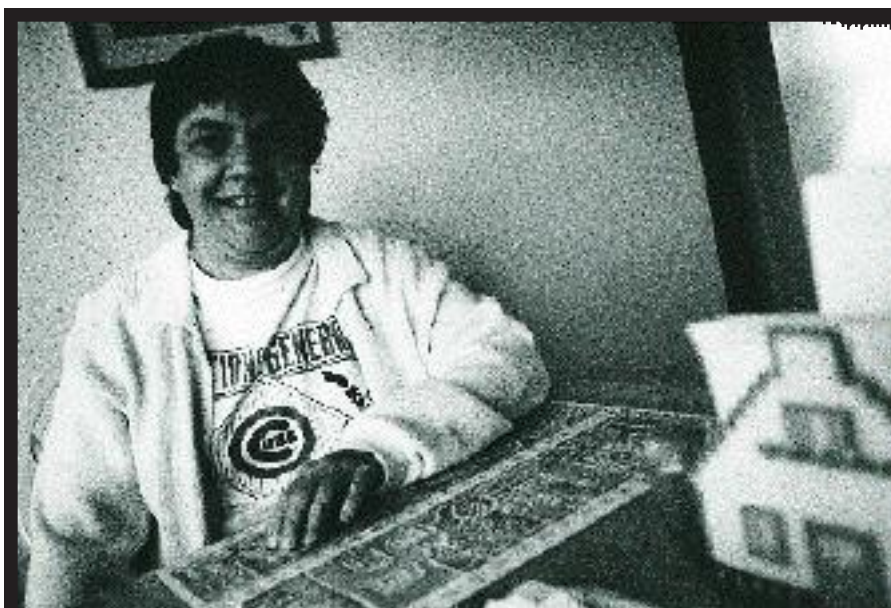
For Organizations. Outcomes for people challenge organizations to individualize services and supports. While previous quality efforts emphasized uniformity in practice and process, personal outcome measures require that organizations tolerate diversity, differentness and non-uniformity. Organizations must now redirect their attention from the uniformity of “programs” to the uniqueness of people.

An outcome focus encourages the service or support entity to identify individual outcomes for *each person* served. Definitions of social participation, friendships, and respect will vary from person to person. Service/support personnel determine how each person defines each personal outcome for him or herself. Services and supports are then developed to address the person’s unique, individual outcomes.

Managing with personal outcomes is different than managing through a departmental or program structure. With personal outcomes, organizations organize resources around people, not programs. There is greater decentralized decision-making and more responsibility for service and support staff. This demands better feedback systems and greater accountability by organizational employees.

The time has come to put “one-size-fits-all” behind us.

The challenge now facing us is to design services and supports around the defined outcomes for people experiencing disabilities.



Employees define their role and responsibility in the context of peoples' outcomes, rather than their job description. In reality, the purpose for employment is to facilitate outcomes; performing job description duties and responsibilities and achieving program goals mean little if those actions do not directly facilitate outcomes for people.

Stakeholders, Barriers and Traditions. Facilitating outcomes requires organizations to think and act outside traditional boundaries. The traditions associated with departmental and program management; program funding, regulation and evaluation; and hierarchical administration are not compatible with personal outcomes.

Our experience indicates that some organizations are able to make the transition. In contrast, other organizations accept the language and values of personal outcomes, but are unable to make the necessary changes in traditional management structure to refocus resources and priorities around people rather than program structures.

Other organizations proclaim that they are prevented from making changes by the funders, legislative and administrative regulation makers, and licensing and certification reviewers. While money is important to organizational efforts to facilitate outcomes, and while there are certainly fiscal, regulatory, and licensing barriers to implementing personal outcomes, the greatest barrier is the lack of organizational and individual creativity. Some service and support staff, professionals, and program managers find it very difficult to think outside of their self-imposed boxes of job descriptions, professional training and program structures.

Facilitating outcomes begins with the simple, but largely ignored, requirement that we understand how the person defines the outcome. Staff then explore the range of resources and processes within their own administrative structure, within the organization, and outside of the organization that can facilitate outcomes.

Professionals and service organizations are committed to working with people with chronic conditions and disabilities. Resources are declining and staff are asked to do more with less. It seems apparent that if we are asking staff to both work hard and competently, we should make sure that they are working on what really matters for people — their own personal outcomes.

So, Can We Forget Organizational Services and Supports?

The increased importance of personal outcomes does not diminish the contribution that organizational services and supports can make to the achievement of outcomes. The Council, however, believes that organizational services and supports can be examined from the perspective of personal outcomes.

Organizational services and supports become important when:

- **we can identify the outcomes that people expect; and**
- **the organizational services and supports are individualized and responsive to personal outcomes.**

Organizations should be aware of the services and supports that are, and are not, successful in assisting people to achieve personal outcomes. Some individualized services and supports may be more successful in residential settings than in the workplace. Some methods may be associated with specific disabilities. For example, the individualized organizational services and supports that enable people to live in integrated environments may vary with disability. People with visual impairments may require types of services and supports different from those needed by a person with a traumatic head injury.

Linking the organizational services and supports to the outcome enables the organization to examine how the organization's activities impact each person. The presence or absence of outcomes for the person is tied into organizational services and supports. This individualization of organizational services and supports provides a better measure of quality than the presence or absence of policy or procedure, which is what would be investigated in a typical process evaluation.

A focus on personal outcomes requires that the person or organization providing supports or services define the type, duration, and intensity of the individualized offering. For example, not all people will need a behavior intervention program. However, people with dysfunctional behaviors might benefit from such a behavioral program. Likewise, human rights committees and behavior intervention committees are not universally required, but outcomes for some people with rights restrictions or intrusive behavioral programs would be enhanced by these additional organizational processes.

Conclusion

Measuring quality through personal outcomes for people is a dramatic departure from past practice. People with disabilities, their families, and advocates are promoting the use of personal outcome measures to determine quality in services and supports. The debate over health care reform and public sector services is placing a greater emphasis on the documented outcomes and services and supports provided.

Personal outcomes have much to offer. The use of personal outcome measures will:

- ▶ **increase the influence of the person experiencing a disability in a service system**
- ▶ **ensure that services and supports are tied to meaningful and measurable outcomes for the person**
- ▶ **maintain a focus on the whole person rather than on the fragmented sectors of the individual's life that fall within funding streams, programs, and regulations**
- ▶ **make service and supports responsive to people**

The time has come to put “one-size-fits-all” behind us. The challenge now facing us is to design services and supports around the defined outcomes for people experiencing disabilities.



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